



# Statement of the U.S. Chamber of Commerce

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**ON:** "GENETIC NON-DISCRIMINATION: EXAMINING THE  
IMPLICATIONS FOR WORKERS AND EMPLOYERS"

**TO:** HOUSE SUBCOMMITTEE ON EMPLOYER-EMPLOYEE  
RELATIONS OF THE COMMITTEE ON EDUCATION AND  
THE WORKFORCE

**BY:** LAWRENCE Z. LORBER

**DATE:** JULY 22, 2004

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The Chamber's mission is to advance human progress through an economic,  
political and social system based on individual freedom,  
incentive, initiative, opportunity and responsibility.

**Statement of Lawrence Z. Lorber  
Partner, Proskauer Rose LLP  
on behalf of the  
United States Chamber of Commerce**

**Before the  
Subcommittee on Employer-Employee Relations  
of the  
House Committee on Education and the Workforce**

**“Genetic Non-Discrimination: Examining the Implications for Workers and  
Employers”**

**July 22, 2004**

**10:30 AM**

Chairman Johnson and Members of the Subcommittee, I am pleased and honored to be here today on behalf of the U.S. Chamber of Commerce to testify about predictive genetic information and the workplace. I am a member of the Chamber’s Labor Relations Committee and Chair of its Equal Employment Opportunity Subcommittee. Thank you for your kind invitation.

By way of introduction, I am a partner with the law firm of Proskauer Rose LLP and have been practicing labor and employment law for almost thirty years both in the government and in private practice. Early in my career, I served in the Office of Solicitor, U.S. Department of Labor, including serving as Executive Assistant to the Solicitor. I was appointed as Deputy Assistant Secretary of Labor and Director of the Office of Federal Contract Compliance Programs (OFCCP), the agency within the Department of Labor that administers the government’s affirmative action and non-discrimination requirements for federal contractors, including the requirements under Section 503 of the Rehabilitation Act of 1973. During my tenure, the initial regulations under the 503 program were issued which established the basis for the enforcement of the non-discrimination and affirmative action requirements in employment for individuals

with handicaps. Those regulations established the principle of job relatedness under the Rehabilitation Act. They also established the principle that there could be no pre-offer inquiry regarding physical conditions. I left that position in 1977 and since then have been in private practice, where I primarily represent employers.

Over the course of my career, I have taken an interest and remained involved in workforce policy issues. This has included, among other things, frequently testifying before Congress and serving as counsel to The Business Roundtable with respect to the 1991 Civil Rights Act. In addition, I was honored to be appointed as one of the original five members of the Board of Directors of the Office of Compliance, the congressional agency established by the Congressional Accountability Act to administer eleven employment statutes, including the Americans with Disabilities Act (ADA), with respect to the Congress and congressional instrumentalities. I remained on the Board until my term was completed in 1998.

Of particular relevance to this hearing, I also act as a technical advisor on the genetics bills introduced in the House and Senate for the U.S. Chamber of Commerce and the Genetics Information Nondiscrimination in Employment (GINE) coalition. The coalition, which is co-chaired by the Chamber, is a group of trade associations and professional organizations formed to address concerns about workplace discrimination based on employees' genetic information as well as the confidentiality of that information.

The issue before us today is whether a new federal law regulating employer collection and use of information about an individual's genetic predispositions to diseases or disorders is necessary at this time, and if so, what form that law should take.

As I will discuss in more detail, these are complex issues and it is certainly appropriate for Congress to review them carefully. A rush to enact broad legislation at this time, however, would be a major mistake.

In this regard, it is extremely important to note that the workplace is already subject to extensive and complex statutory and regulatory oversight by federal, state, and local government. This has created a confusing matrix of overlapping requirements administered by a multitude of different agencies. Each one of these laws and regulations imposes a cost on our economy and, while in many cases providing important

protections, also opens the door to abusive, frivolous, and costly litigation. Therefore, as a matter of sound policy there ought to be a reluctance to add to this mass of regulation.

If, however, it is determined that Congressional action is warranted, any response should be narrowly targeted and consistent with the substantial body of law already governing employer collection and use of genetic and other health information. It also must be designed to minimize unnecessary and overly complex regulation, frivolous litigation, and unforeseen consequences.

Unfortunately, the bills currently before Congress completely fail to meet these criteria. In order to understand why this is the case, some background is necessary.

## **I. Protections Under Existing Law**

Existing federal laws already provide substantial protections against employer acquisition, disclosure, and misuse of genetic information. States have also enacted a variety of laws, some of which specifically regulate the collection and use of genetics information in the workplace, others of which deal more generally with the issue of the confidentiality of medical information.

### **A. The Americans with Disabilities Act**

Among other things, the ADA created a comprehensive scheme regulating employer collection and disclosure of medical information and providing protections for the disabled against employment discrimination.

The Equal Employment Opportunity Commission (EEOC), which is the federal agency charged with enforcing ADA provisions on employment, has made it clear to employers that, in its opinion, the ADA provides protections against collection and disclosure of genetic information as well as employment discrimination based on an individual's genetic makeup.<sup>1</sup> The agency has also made it clear that it has no compunction about bringing an enforcement action under the ADA against an employer engaged in such behavior. Specifically, it has said that "the Commission will continue to respond aggressively to any evidence that employers are asking for or using genetic tests

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<sup>1</sup> See EEOC's Memorandum in Support of Petition for Preliminary Injunction, *EEOC v. Burlington Northern Santa Fe Railroad*, (N.D. IA, settled April 18 2001); *EEOC Compliance Manual*, section 902: Definition of the Term Disability, Sec. 902.8(a); *EEOC Enforcement Guidance: Disability-Related Inquiries and Medical Examinations of Employees Under the Americans with Disabilities Act*, available at <http://www.eeoc.gov/policy/docs/guidance-inquiries.html>.

in a manner that violates the ADA . . . . Employers must understand that basing employment decisions on genetic testing is barred under the [ADA and, m]oreover, genetic testing, as conducted in this case, also violates the ADA as an unlawful medical exam.”<sup>2</sup> The EEOC’s position that the ADA provides these protections certainly belies the argument that there is a gap which must be filled by federal legislation.

#### *ADA & Discrimination*

There are two theories under which the ADA can be interpreted to bar discrimination based on genetic makeup.

The first, which has been advocated by the EEOC, is based on the ADA’s “regarded as” prong. To be protected from employment discrimination under the ADA, an individual must have one of the following: an actual disability, a record of such a disability, or be regarded as having a disability. The EEOC has taken the position that discrimination based on genetics is tantamount to discrimination against an individual because he or she is regarded as having a disability.<sup>3</sup> The agency’s position, which is clearly articulated in its compliance manual, is based in part on explicit statements in the ADA’s legislative history.<sup>4</sup>

While some have hypothesized that the EEOC’s theory may not hold up to judicial scrutiny,<sup>5</sup> it was the foundation for the Commission’s suit and favorable settlement in the only recorded case where a private employer was accused of genetic discrimination.<sup>6</sup> In the settlement, the employer agreed to pay \$2.2 million to 36 workers, not engage in any further genetic testing of employees or applicants, provide

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<sup>2</sup> *EEOC Settles ADA Suit Against BNSF For Genetic Bias*, EEOC Press Release (April 18, 2001), available at <http://www.eeoc.gov/press/4-18-01.html>.

<sup>3</sup> See *EEOC’s Memorandum in Support of Petition for Preliminary Injunction, EEOC v. Burlington Northern Santa Fe Railroad*, (N.D. IA, settled April 18, 2001); *EEOC Compliance Manual*, section 902: *Definition of the Term Disability*, Sec. 902.8(a) (“Covered entities that discriminate against individuals on the basis of genetic information are regarding the individuals as having impairments that substantially limit a major life activity.”); Testimony of EEOC Commissioner Paul Steven Miller Before the Senate Committee on Health, Education, Labor and Pensions (July 20, 2000).

<sup>4</sup> *EEOC Compliance Manual*, section 902: *Definition of the Term Disability*, Sec. 902.8(a) (citing 136 Cong. Rec. H4623 (daily ed. July 12, 1990) (statement of Rep. Owens), at H4624-25 (statement of Rep. Edwards), and at H4627 (statement of Rep. Waxman)).

<sup>5</sup> See, e.g., Testimony of Andrew J. Imparato Before the Senate Committee on Health, Education, Labor and Pensions (February 13, 2002); see also Testimony of EEOC Commissioner Paul Steven Miller Before the Senate Committee on Health, Education, Labor and Pensions (July 20, 2000) (expressing concerns over language in the *dissent* in *Bragdon v. Abbott*, 524 U.S. 624 (1998)).

<sup>6</sup> See *EEOC’s Memorandum in Support of Petition for Preliminary Injunction, EEOC v. Burlington Northern Santa Fe Railroad*, (N.D. IA, settled April 18, 2001).

enhanced ADA training to its medical and claims personnel, and have senior management review all significant medical policies and practices.<sup>7</sup> Given the end result of the case and the public relations damage associated with an EEOC suit, we do not believe that it is reasonable to expect that there are any employers that are anxious to “test” the “regarded as” theory in court.

Several commentators have advanced a second theory under which the ADA may bar genetics discrimination. Under this theory, the mere possession of a genetic marker for a disease could constitute an actual (opposed to being “regarded as” having a) disability under the ADA, even though the individual has not manifested symptoms of the underlying disease.<sup>8</sup> The theory is based on the 1998 the Supreme Court case *Bragdon v. Abbott*.

In *Bragdon*, the Court found that asymptomatic HIV (i.e., the disease had not progressed to the symptomatic stage) is a disability under the ADA.<sup>9</sup> It reasoned that even though symptoms of the disease had not yet manifested, the danger of passing HIV on to one’s partner or children substantially limited the major life activity of reproduction.<sup>10</sup> With respect to offspring, the same could be said about certain genetic disorders.<sup>11</sup>

Of course, whether or not the genetic marker substantially limits reproduction will depend on the likelihood of passing it to one’s children. In the *Bragdon* case, the Court found an 8% risk of passing on the disease significant enough to substantially limit reproduction.<sup>12</sup>

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<sup>7</sup> *EEOC Settles ADA Suit Against BNSF For Genetic Bias*, EEOC Press Release (April 18, 2001), available at <http://www.eeoc.gov/press/4-18-01.html>; *EEOC's First Genetic Testing Challenge Settled for \$2.2 Million, Parties Announce*, BNA The Daily Labor Report (May 9, 2002).

<sup>8</sup> See, e.g., Testimony of Andrew J. Imparato Before the Senate Committee on Health, Education, Labor and Pensions (February 13, 2002).

<sup>9</sup> *Bragdon v. Abbott*, 524 U.S. 624 (1998).

<sup>10</sup> *Id.* at 640-41.

<sup>11</sup> The ADA defines an actual disability as an impairment that substantially limits a major life activity. While a marker for a genetic disorder certainly might substantially limit reproduction in the same manner as HIV, it is not completely settled whether a court would find that a genetic predisposition to a disease constitutes an impairment. Under the ADA, an impairment is a condition which affects one of the body’s key systems. The Court in *Bragdon* concluded that “[i]n light of the immediacy with which the virus begins to damage the infected person’s white blood cells and the severity of the disease, we hold [that HIV] is an impairment from the moment of infection.” 524 U.S. at 638. A court may or may not come to the same conclusion with regard to any given genetic marker.

<sup>12</sup> 524 U.S. at 641.

### *The ADA & Collection & Disclosure of Information*

There are also provisions in the ADA governing employer acquisition and disclosure of genetic information. The section of the statute regulating acquisition provides distinct rules for different stages of the employment relationship. Courts have found that these restrictions apply regardless of whether the applicant or employee is disabled.<sup>13</sup>

Applicants are provided the greatest protections. The ADA specifically prohibits medical examinations or any disability-related inquiries of job applicants. According to EEOC guidance, this means employers may not ask applicants any questions “likely to elicit information about a disability, [including those] about an employee’s genetic information” and may not require applicants undergo medical examinations, including genetic tests.<sup>14</sup>

After an applicant receives an offer but before he or she begins employment, however, an employer may ask disability-related questions, including those concerning genetic-related information, and require that the employee undergo medical examinations, including genetic tests. The provision allows employers to obtain important information regarding the employee’s ability to perform the job in a safe manner—information that may be unbeknownst to an employee until the medical examination or inquiry.

The examinations and inquiries are only permitted, however, if the employer makes the same inquiries and requires the same tests of every person with an offer in that job category. This ensures that individuals, or classes of individuals, are not singled out for inquiries or examinations.

Once a person begins employment, the ADA only permits employers to make medical inquiries or require medical exams that are job related and consistent with business necessity. This allows employers to acquire specific targeted information that

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<sup>13</sup> See, e.g., *Cossette v. Minnesota Power and Light*, 188 F.3d 964 (8<sup>th</sup> Cir. 1999); *Fredenburg v. Contra Costa County Dep’t of Health Servs.*, 172 F.3d 1176, 1182 (9<sup>th</sup> Cir. 1999); *Roe v. Cheyenne Mountain Conference Resort, Inc.*, 124 F.3d 1221, 1229 (10<sup>th</sup> Cir. 1997).

<sup>14</sup> *EEOC Enforcement Guidance: Disability-Related Inquiries and Medical Examinations of Employees Under the Americans with Disabilities Act*, available at <http://www.eeoc.gov/policy/docs/guidance-inquiries.html>. The guidance defines genetic information as information about an individual’s genetic tests, genetic tests of his or her family members, or the occurrence of a disease, medical condition, or disorder in his or her family members.

may be necessary to ensure a safe workplace or to provide benefits under employer policies or federal or state laws, or to provide an employee with a reasonable accommodation as required by the ADA and similar state laws.

The ADA requires, however, that employers keep any health information they acquire from post-offer applicants or employees in confidential separate files only to be revealed to:

1. first aid and safety personnel, if emergency treatment may be needed;
2. supervisors, as it pertains to the individual's work restrictions; or
3. government officials.

Also, the information may not be used to discriminate in violation of the ADA or any other federal or state statute for that matter. Thus, even if an employer collected genetic information, it could not base an employment decision on the information without the threat of liability under ADA, or other federal or state laws.

**B. The Health Insurance Portability and Accountability Act**

In addition to the protections afforded by the ADA, the Health Insurance Portability and Accountability Act (HIPAA) regulations restrict employer collection, use, and disclosure of genetic information acquired through the administration of employer sponsored group health plans. Although the HIPAA regime does not directly govern the employment relationship, HIPAA prohibits group health plans and insurers from providing employers with employees' and beneficiaries' health information, including genetic information, unless certain requirements are met. More specifically, in order to receive health information, the employer/plan sponsor essentially must amend the plan to include assurances that it will only use the information for plan administration with specific guarantees that it will not use the information for employment decisions. The regulations also require that employers who provide group health plans create a firewall to separate plan administration from human resource functions. Violations can result in severe criminal penalties.<sup>15</sup>

**C. Title VII of the Civil Rights Act of 1964**

Title VII of the Civil Rights Act of 1964 (Title VII), in certain circumstances, also prohibits genetic testing/inquiries and discrimination based on genetic makeup. Title VII

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<sup>15</sup> \$250,000 and 10 years in prison, *see* 42 U.S.C. sec. 1320d-6.



bars employers from discriminating based on race, color, religion, sex, or national origin. Although on its face the statute may not appear to protect against genetic discrimination, it does prohibit employers from singling out a certain group for testing or inquiries.

This was exactly the situation in a case against Lawrence Berkley Laboratory, a research institution jointly operated by state and federal agencies. As part of its occupational medical program, the laboratory required prospective employees (those who had been given a conditional offer), to undergo medical examinations, including testing of African American candidates for the sickle cell anemia trait. Sickle cell anemia is the most common inherited blood disorder in the United States, affecting about 72,000 Americans or 1 in 500 African Americans.<sup>16</sup> Several employees sued and the United States Court of Appeals for the Ninth Circuit ruled that by singling out African Americans for the test, the laboratory violated Title VII.<sup>17</sup>

Likewise, Title VII would prevent employers from singling out women for tests for BRCA 1 and BRCA 2 genes, which can reveal a predisposition for breast and ovarian cancer.<sup>18</sup>

Title VII also bars discrimination based on genetic traits, if the discrimination has a disproportionate adverse effect on individuals of a certain race, sex, color, or national origin. For example, the genetic mutation associated with Tay-Sachs Disease is found most commonly in persons with an Eastern European Jewish ethnic background.<sup>19</sup> As was aptly pointed out by the Senate Committee on Health, Education, Labor and Pensions in its Committee Report on S. 1053, “if an employer were to selectively refuse to hire carriers of the Tay-Sachs mutation, this action would have a disproportionate effect on people with a specific national or ethnic origin . . .” and thus may constitute a violation of Title VII.<sup>20</sup> This would hold true for many genetic mutations, including BRCA 1 and BRCA 2 (more prevalent among those with Ashkenazi (Eastern European)

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<sup>16</sup> Information provided by the National Institutes of Health, available at <http://www.ncbi.nlm.nih.gov/books/bv.fcgi?call=bv.View..ShowSection&rid=gnd.section.98>.

<sup>17</sup> *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, 135 F.3d 1260, 1272 (9<sup>th</sup> Cir. 1998).

<sup>18</sup> See *Genetic Testing for BRCA 1 and BRCA 2: It's Your Choice, Cancer Facts*, National Cancer Institute, available at [http://cis.nci.nih.gov/fact/3\\_62.htm](http://cis.nci.nih.gov/fact/3_62.htm).

<sup>19</sup> See *The National Tay-Sachs and Allied Diseases Association web site*, available at <http://www.ntsad.org/pages/t-sachs.htm>.

<sup>20</sup> Senate Committee on Health, Education, Labor and Pensions in its Committee Report on S. 1053, 108<sup>th</sup> Congress, at 11.

Jewish ancestry),<sup>21</sup> Hemophilia (a genetic blood clotting disorder primarily affecting males)<sup>22</sup> or Fragile X-associated Tremor/Ataxia Syndrome (a genetically neurological disorder which only affects men).<sup>23</sup>

Nor could an employer specifically discriminate against a subgroup of individuals with the gene, if that subgroup is a class protected by Title VII. For example, it would be unlawful sex discrimination to refuse to hire women with BRCA 1 and BRCA 2 genes, unless the employer also refused to hire men with the genes.

#### D. State laws

There are 32 states that have laws specifically prohibiting employment discrimination based on genetic makeup, 26 have laws specifically regulating employer acquisition and disclosure of genetic information, and more than 25 states have laws regulating the privacy of genetic information.<sup>24</sup> Forty-nine states have laws protecting against disability discrimination similar to the ADA, which also may provide protections.<sup>25</sup> All states have laws with some restriction on access and disclosure of medical information.<sup>26</sup>

## II. **Case for Congressional Consideration of Additional Regulation**

### A. Given the Lack of Appreciable Evidence of Genetic Discrimination or Misuse of Genetic Information and Existing Laws Regulating Genetics in the Workplace, Further Regulation Aimed at Creating Additional Deterrents Appears Unnecessary at This Time

There is little to no evidence of employer collection or misuse of genetic information in today's workplace. This is despite continued predictions that, in the absence of a bill, the fear of increased insurance costs, absenteeism, and low productivity would inevitably drive vast numbers of employers to genetic testing of the workforce and

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<sup>21</sup> See *Genetic Testing for BRCA 1 and BRCA 2: It's Your Choice*, Cancer Facts, National Cancer Institute, available at [http://cis.nci.nih.gov/fact/3\\_62.htm](http://cis.nci.nih.gov/fact/3_62.htm).

<sup>22</sup> See <http://www.hemophiliagalaxy.com/patients/about/index.html>.

<sup>23</sup> See *Fragile X-associated Tremor/Ataxia Syndrome*, Paul J. Hagerman, M.D., Ph.D and Randi J. Hagerman, M.D., available at <http://fragilex.org/FXTAS.pdf>.

<sup>24</sup> National Conference of State Legislatures, available at <http://www.ncsl.org/programs/health/genetics/charts.htm>.

<sup>25</sup> *Id.*, available at <http://www.ncsl.org/programs/employ/empdisc.htm>.

<sup>26</sup> *Id.*, available at <http://www.ncsl.org/programs/health/genetics/charts.htm>.

employment discrimination based on genetic makeup.<sup>27</sup> Whether it is due to the threat of liability under existing protections, fear of public backlash, moral concerns, or simply a lack of interest, employer collection and misuse of genetic information remains largely confined to the pages of science fiction.

Indeed, there is but one recorded case alleging inappropriate collection and misuse of employee genetic information by a private employer. As I said before, the EEOC prosecuted that company under the ADA and, through settlement, recovered over \$2 million for the affected employees in addition to injunctive relief.

Despite this lack of evidence, proponents of broad genetic legislation continue to claim that a new law imposing significant compliance costs is necessary in order to deter employers from collecting and misusing genetic information. Yet, if anything, the lack of litigation under available avenues of redress, such as the ADA, Title VII, and the multitude of state laws, indicates that existing legal protections are a more than adequate deterrent against employer collection and misuse of genetic information.

Let me speak plainly. Even assuming for the purposes of argument that some number of employers were disposed to engage in genetic discrimination, the threat of allegations of discrimination from both a liability and public relations perspective is enough to prevent these employers from ever contemplating acquiring any genetic information. The simple fact is if they never have the information, they cannot be accused of using it to discriminate.

Many of the proponents of broad legislation have attempted to prop up their weak case by alleging—without factual support—that employer misuse of genetic information is prevalent. For example, the Council for Responsible Genetics contends that there have been hundreds of instances of genetic discrimination by employers and insurers.<sup>28</sup> Yet, the group produces no hard statistical data supporting its claim. Given the existing protections under federal and state law and the aggressiveness of the trial bar with respect

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<sup>27</sup> See, e.g., Melinda Kauffman, *Genetics Discrimination in the Workplace: an Overview of Existing Protections*, 30 Loy. U. Chi. L.J. 393, 395 (1999); Testimony of Andrew J. Imparato Before the Senate Committee on Health, Education, Labor and Pensions (February 13, 2002); Testimony of the National Partnership for Women and Families Before the House Subcommittee on Employer-Employee Relations (July 24, 2001).

<sup>28</sup> The Council for Responsible Genetics: Genetic Testing, Discrimination and Privacy, available at <http://www.gene-watch.org/programs/privacy.html>.

to employment litigation, it is highly unlikely that none of these people would have sought legal redress.<sup>29</sup>

There have also been attempts to misleadingly characterize the available research to suggest that employers are routinely performing genetic tests on their employees. For example, some proponents cite research conducted in 1989 for the now defunct Office of Technology Assessment (OTA).<sup>30</sup> The OTA reported that, in a survey of Fortune 500 companies, 12 employers reported conducting genetic tests. However, as it turns out these tests were not for nefarious purposes at all, but rather they were performed as part of a voluntary wellness program, or other tests performed at the employee's request, and tests performed as part of diagnosing an employee's medical condition.<sup>31</sup> The OTA study most certainly did not demonstrate that employers were systematically using genetic information to make adverse personnel decisions. In fact, of the universe samples, only a single employer reported making an adverse employment decision based on genetic information.<sup>32</sup>

Likewise, proponents have cited survey research performed by the American Management Association (AMA) of 2,133 companies in which three employers (in 1999) and seven employers (in 2000) reportedly utilized genetic tests of some of their employees. What proponents leave out is that the AMA also noted that "unanimously, the companies that did genetic tests told us they performed them for no other reason than concerns over workplace safety and health."<sup>33</sup> Likewise proponents misleadingly fail to report that in the last survey year with available data, 2001, only two employers reported performing any such tests. As the AMA concluded, "if genetic testing is being done to

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<sup>29</sup> Employees may not be aware of existing protections until they face genetic testing or discrimination in the workplace, and, as I discuss later, this lack of information could discourage people from seeking genetic tests. Once an employee is faced with genetic testing or genetic discrimination in the workplace, however, such protections are quickly revealed by a simple search on the internet or trip to the local trial attorney.

<sup>30</sup> OTA, which operated from 1972 to 1995, was designed to assist Congress with the complex and technical issues that impacted society.

<sup>31</sup> *Genetic Monitoring and Screening in the Workplace*, Office of Technology Assessment, at 171-93 (1990).

<sup>32</sup> *Id.* at 182.

<sup>33</sup> See Testimony of Eric Greenberg Before the House Subcommittee on Employer-Employee Relations (July 24, 2001).

any appreciable degree among AMA membership and client base that together employ about one-fourth of the American work force, we haven't been able to find it."<sup>34</sup>

B. Is Fear of Discrimination Discouraging Testing and Participation in Research?

Some also claim that legislation is necessary to promote genetic testing and research. More specifically, they allege that some individuals are failing to seek out genetic testing and avoiding participating in genetic research because they are afraid that results of the test will be used to deny them or their family members employment opportunities.<sup>35</sup> These claims are based on several surveys that have been conducted in the last decade.

The Chamber believes that public policy should not allow fear of genetic discrimination to discourage individuals from seeking health information that will assist in the diagnosis and treatment of possible illnesses or participating in research that contribute to the evolution of genetic science. Rather it believes that sound public policy should make it clear that such fears are unfounded under the laws and protections in effect today.

### **III. Devising an Appropriate Response to Possible Problems**

The surveys on genetic testing and fear of discrimination should be the starting place for further Congressional investigations into the matter. If it is determined that such fear does exist and is discouraging genetic testing and/or research, Congress should weigh the various possible solutions, including increasing education about existing legal protections to employees,<sup>36</sup> or if necessary, enacting targeted legislation that protects against discrimination based on the results of genetic tests. If drafted correctly, such a

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<sup>34</sup> *Id.* (emphasis added)

<sup>35</sup> Of course, the ongoing drumbeat by proponents of legislation that existing laws provide insufficient protections against genetics discrimination, coupled with their accusations that employers are engaged in widespread discrimination, are likely to have exacerbated any misplaced fears that exists regarding employer misuse of genetic information.

<sup>36</sup> For example, nowhere in the EEOC's posters that employers must post at the workplace does it mention that it is the agency's position that the ADA prohibits discrimination based on genetic discrimination and regulates the collection and disclosure of genetic information. Nor is there any information contained in it about the possible protections offered under Title VII. Thus, while many employers may be aware of the EEOC's position, employees may not be as well informed.

bill could get to the root of the problem (if there is indeed one) without imposing undue transactional compliance and litigation costs.

Congress should not, however, rush to pass broad sweeping legislation where there is no evidence that greater protections are needed to prevent against inappropriate collection and use of genetic information in the workplace—above all at a time when over regulation is already choking our economy.<sup>37</sup>

It is extremely important to again note that the workplace is subject to an already extensive and complex statutory and regulatory scheme and, that as a matter of sound policy, Congress should be reluctant to add to this mass of regulation, particularly where there has been no evidence that existing protections are somehow inadequate, or, indeed, that there is even a compelling problem that needs to be addressed by sweeping federal legislation.

Furthermore, even if Congress was presented with evidence that existing laws somehow are failing to provide the necessary protections, the bills currently before it, namely S. 1053 and H.R. 1910, would not be appropriate responses. There are numerous reasons for why this is the case, most of which are laid out in the attached letter from the GINE Coalition to the Senate. There are, however, two additional points worth making.

First, neither bill is consistent with the existing law. Both create new regulatory schemes governing how employers handle genetic information—schemes which differ substantially from those under the ADA.

For example, under the ADA, an employer may request medical information of an employee if doing so is job related and consistent with business necessity and may only disclose that information to medical personal, supervisors (if the information is relevant to work restrictions), and the government. Rather than using these same criteria, S. 1053 and H.R. 1910 create a broad prohibition against acquisition and disclosure of genetic information and a laundry list of exemptions for specific situations.

Thus, employers would face one set of rules for how they handle genetic information and an altogether different one for how they handle all other health information. This is despite the fact that as genetic science progresses it will be difficult

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<sup>37</sup> See, e.g., W. Crain, T. Hopkins, *The Impact of Regulatory Costs on Small Firms*, Report RFP No. SBAHQ-00-R-0027, The Office of Advocacy, U.S. Small Business Administration (July 2001) (estimating the cost federal regulations at about \$843 billion).

for trained technicians, let alone human resources professionals, to separate the two.<sup>38</sup> Furthermore, from a practical perspective, employers would be required to keep health information and genetic information in two separate files, leading not only to administrative and compliance burdens, but vastly increasing the chance that information important to the health and safety of the employee or others in the workforce is overlooked in a crucial moment.

Both bills also suffer from drafting problems. For instance, both would allow plaintiffs to use existing legal theories under Title VII to sue employers for failing to provide health coverage for specific genetic-related conditions. According to the EEOC, sex and pregnancy discrimination provisions of Title VII require that employers who provide comprehensive health insurance also offer coverage for gender specific drugs, such as oral contraceptives.<sup>39</sup> The only court to address the issue has agreed with the EEOC's interpretation.<sup>40</sup> S. 1053 and H.R. 1910 borrow language from the relevant provisions in Title VII; thus, if these bills were to become law, the theory could be applied in the context of genetics.

Permitting lawsuits for yet another health care mandate would be troubling. This was clear to the Clinton Administration, which specifically stated in its executive order barring genetic discrimination against federal employees that “[n]othing in this order shall be construed to . . . require specific benefits for an employee or dependent under the Federal Employees Health Benefits Program or similar program.”<sup>41</sup>

These types of drafting problems are particularly troublesome when the legislation is regulating such an important and rapidly developing area. As was noted before this Subcommittee in 2001, legislating on such a dynamically developing subject matter can be fraught with potential missteps and “several states already have updated laws enacted years before and many lawmakers foresee the need to regularly review state genetics policies to account for new developments and guard against unforeseen

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<sup>38</sup> See, e.g., *Mutated Gene Can Help Drug Combat Cancer*, Wall Street Journal, April 30, 2004.

<sup>39</sup> *Commission Decision on Coverage of Contraceptives*, available at <http://www.eeoc.gov/policy/guidance.html>; *Question and Answers: Commission Decision on Coverage of Contraceptives*, available at <http://www.eeoc.gov/policy/guidance.html>.

<sup>40</sup> *Erickson v. The Bartell Drug Company*, 141 F. Supp.2d (W.D. Wash. 2001).

<sup>41</sup> Executive Order 13145, 1-402(b).

consequences.”<sup>42</sup> As EEOC Chair Cari Dominguez said in testimony before the Senate Committee on Health, Education, Labor and Pensions “we need to be careful that we do not create overly inflexible restrictions that inhibit beneficial uses of this information.”<sup>43</sup>

Both the inconsistency with existing law and drafting problems also invite unnecessary and abusive litigation and costly regulation. This is particularly true with respect to laws governing the workplace, where employers already face vast amounts of costly litigation, which, unfortunately is often unwarranted. In 2003, for example, the EEOC only found cause in 5.7% of the over 87,000 charges that it resolved and found absolutely no cause for discrimination in 63.1% of the charges (amounting to over 55,000 “no cause” findings).<sup>44</sup> With respect to S. 1053 and H.R. 1910, this would certainly be exacerbated by the fact that both bills call for recovery of punitive and compensatory damages and jury trials. H.R. 1910 is particularly objectionable in that it allows unlimited damages and it would permit a plaintiff to bypass the administrative and dispute resolution functions of the EEOC.

#### **IV. Conclusion**

As a representative of employers and as a leader in trying to increase health insurance coverage, the Chamber is excited about the potential of genetic science leading to more effective treatments and early interventions.

However, we just as strongly believe that an additional broad workplace regulatory regime is unnecessary at this time. Science is not assisted by over regulation and frivolous litigation, and we appreciate this opportunity to highlight the extensive existing protections against genetic discrimination, as well as the complete lack of evidence that employers are engaged in the collection and misuse of genetic information.

To the extent that greater education about existing law or targeted legislation is needed to allay fears, however misplaced, we are ready to work with the Congress to address this issue.

Thank you. That concludes my prepared remarks.

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<sup>42</sup> Testimony of Chye Calvo Before the House Before the House Subcommittee on Employer-Employee Relations (July 24, 2001).

<sup>43</sup> Testimony of Cari Dominguez Before the Senate Committee on Health, Education, Labor and Pensions (February 13, 2002).

<sup>44</sup> EEOC enforcement statistics, available at <http://www.eeoc.gov/stats/all.html>.





# Genetic Information NonDiscrimination in Employment Coalition

June 12, 2003

[Address]

RE: S. 1053, the Genetic Information Nondiscrimination Act of 2003

Dear Senator [ ]:

We write on behalf of the Genetic Information Nondiscrimination in Employment (GINE) Coalition to express our concerns with S. 1053.

The GINE Coalition is a group of employers, national trade associations, and professional organizations formed to address concerns about workplace discrimination based on employees' genetic information as well as the confidentiality of that information. The Coalition firmly supports a policy of nondiscrimination and confidentiality, and believes that employment decisions should be based on an individual's qualifications and ability to perform a job, not on characteristics that have no bearing on job performance. We also believe, however, that any legislation on this issue must be carefully designed to minimize uncertainties, unintended consequences, and unwarranted litigation. To this end, the Coalition, while at times questioning the need for legislation, has worked diligently with Congress over the past several years, consistently advocating that any legislation be fair, reasonable, and narrowly drafted.

On May 21, 2003, the Senate Health, Education, Labor, and Pensions Committee approved S. 1053 – Title II of which is the most recent incarnation of workplace genetics legislation.<sup>1</sup> While the bill is a vast improvement over S. 16 – introduced earlier this year by Minority Leader Daschle – aspects of S. 1053, nonetheless, remain extremely troubling. More specifically, certain overly broad provisions in the bill conflict with other laws, and may invite unwarranted litigation and unnecessary regulation.

## General Concerns with S. 1053's Breadth

The driving force for this legislation is not an ongoing practice of discrimination or mishandling of genetic information. Indeed, there is no appreciable evidence of possession or usage of genetic information by employers. Rather, the bill's supporters argue that legislation is needed to prevent *possible* future misconduct and, more importantly, to ensure that individuals do not hesitate to avail themselves of genetic tests out of fear of employer discrimination.

Legislating based on theoretical discrimination and predictions of future behavior, however, is fraught with opportunities for unintended consequences, unnecessary regulation, and unwarranted litigation. It also sets a new precedent, as Congress has never created a new cause of action against employers based on potential or theoretical discrimination, only on some appreciable history of actual discrimination. For these reasons, any bill you enact must be *clearly* and

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<sup>1</sup> Title I of S. 1053 addresses issues related to genetics and insurance coverage. Although certain individual Coalition members may have views on Title I, the Coalition's comments are limited to Title II of the bill.

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## Genetic Information NonDiscrimination in Employment Coalition

*narrowly* drafted and *only* address the problem that has fueled its creation – in this case – that the fear of possible discrimination may deter employees from availing themselves of genetic tests.

This is particularly important given that the Americans with Disabilities Act (ADA) and the regulations under the Health Insurance Portability and Accountability Act already provide significant protections against collection, disclosure, and discrimination based on medical information, including any medical information containing genetic information. Obviously, further legislation in this area should be consistent with these existing laws.

Legislators should also keep in mind the vast and costly amount of litigation employers face under current discrimination laws, and, unfortunately, that much of this litigation is unwarranted. In 2002, for example, the Equal Employment Opportunity Commission only found reasonable cause in 7.2% of the nearly 85,000 charges of discrimination that it received – and found absolutely no cause for discrimination in almost 60% of the charges (amounting to 55,000 “no cause” charges). A study of previous years’ statistics yields similar results.

Our concerns over frivolous litigation are heightened by the fact that S. 1053 provides for jury trials and recovery of compensatory and punitive damages. We strongly question the need for such remedies. The availability of non-economic damages and jury trials arguably may be justified based on a record of discrimination, as was the case with the 1991 Civil Rights Act, but is hard to justify in the case of genetic discrimination, where equitable relief (which could include agency enforcement and lost wages and attorney fees) should be sufficient to ensure that employers do not begin discriminating based on genetic information.

In short, it is important that new discrimination legislation be narrowly tailored to achieve the stated goal of its proponents, which brings us to our specific concerns about S. 1053. Attached is a list of these concerns. We hope that we can work with you to address some of these issues as the bill moves through the legislative process.

Please contact us if you would like to discuss these matters further.

Very Truly Yours,

The GINE Coalition Steering Committee:

U.S. Chamber of Commerce  
Society for Human Resource Management  
National Association of Manufacturers  
LPA, The HR Policy Association  
College and University Professional Association for Human Resources

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# Genetic Information NonDiscrimination in Employment Coalition

## S. 1053

### *Limit the Scope of S. 1053 to Genetic Tests*

The driving force for this legislation is not an ongoing practice of discrimination or mishandling of genetic information, but, rather that the fear of possible discrimination may deter employees from availing themselves of genetic tests. Accordingly, S. 1053 *only* should prohibit employers from discriminating based on genetic tests, not family history that could be – and most times is – completely unrelated to tests. This would greatly minimize the opportunity for unintended consequences and unnecessary litigation under the bill, while also thoroughly addressing the issue which fueled the bill's creation. It would also greatly reduce the probability that the bill will conflict or complicate compliance with other laws, such as the Americans with Disabilities Act (ADA).

### *Narrow the Definition of Family Member*

If there must be a cause of action based on family history, then it should be of reasonable scope. S. 1053 defines family members as *any* individual related by blood or *any* individual related by blood to a child placed for adoption with the employee no matter how remote the relation. This is merely an opportunity for plaintiffs' attorneys to exploit, and an invitation for frivolous litigation. The bill only should cover situations where the information is scientifically proven to reveal patterns of inheritance of genetic conditions and is useful for medical diagnosis in the employee and his or her immediate family.

### *An Independent Commission*

S. 1053 would require the creation of a commission six years after the bill's enactment to "review the developing science of genetics and to make recommendations to Congress regarding whether to provide a disparate impact cause of action under this act." The Commission, to be known as the Genetic Nondiscrimination Study Commission, is to be housed and funded by the Equal Employment Opportunity Commission (EEOC).

While the Coalition has no objection to the Genetic Commission, we do object to tying both its housing and funding to the EEOC. No one would ever suggest that the business trade association or law firm that regularly defended claims made under S. 1053 would be an appropriate source of funding or housing for the Commission. So too, it should be with the EEOC – the agency tasked with **prosecuting** violations of the bill. Clearly, the EEOC will have its own views on what changes should be made to genetics legislation, and it is unlikely those views would be objective. By tying the Commission's housing and funding to the EEOC, it is inevitable that the Commission will be largely staffed with former or current EEOC employees – some of whom will have been responsible for prosecuting claims under S. 1053. To prevent this undue influence, the Commission should be funded and housed independent of the EEOC.

### *Expanded Commission & Sunset*

Any genetic nondiscrimination legislative proposal should contain a mechanism to ensure that public policy keeps pace with future scientific advances. Given the rapid evolution in the field, legislation drafted now is unlikely to anticipate developments in genetic science that could occur even in the *near* future. As demonstrated by state experience – where several states were compelled to revisit their original legislation – unintended consequences can sometimes force the legislature to rewrite legislation within just a few years. Thus, the Genetic Nondiscrimination Study Commission should study and report on all aspects of the bill – as its name implies – not just disparate impact. The bill should also provide for a sunset date, at which time Congress may consider new issues related to genetic discrimination raised by the Commission and adjust

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# Genetic Information NonDiscrimination in Employment Coalition

the legislation accordingly. Such a model creates a powerful incentive for Congress to revisit the law and make appropriate modifications.

## *Direct Threat - Protecting Employees and the Public*

The ADA, Title VII of the Civil Rights of 1964, and other discrimination laws recognize that there can be rare cases where an employer has a legitimate reason to make employment decisions based on information that would otherwise be protected. Courts have interpreted these exceptions extremely narrowly but have recognized that employers can have valid reasons for such policies. For example, under the ADA, a health condition likely to cause uncontrollable seizures could properly be considered a “direct threat” to safety if the employee were a bus driver, thus justifying an employment decision that would otherwise be unlawful. A similar narrow exception should exist for genetic discrimination. If science progresses to the point where it is possible to determine that an individual is virtually certain to have a health condition which poses “a direct threat” – such as an uncontrollable seizure when driving a bus – then employers should be able to make employment decisions based on this information in order to protect employees, customers and the public. Thus, we propose adding the following language, which mirrors that of the ADA: “Nothing in this bill shall be construed to prohibit an employer from requiring that an individual not pose a direct threat to the health and safety of other individuals in the workplace.”

## *Safe Harbor*

Any legislation should recognize the problems faced by employers as they try to comply with the numerous genetic discrimination laws already in existence. More than 30 states have enacted laws prohibiting discrimination based on genetic information. However, these laws vary widely from state to state. If Congress enacts legislation barring employment discrimination based on genetic information then it should include a safe harbor providing that employers in compliance with the federal standards cannot be liable under state or local laws banning such discrimination.

## *Choice of Remedies*

In the only recorded case where an employer was accused of engaging in genetic testing and genetic discrimination, the individual plaintiffs filed claims against their employer with the EEOC, which, in turn, sued the employer under the ADA. The agency successfully settled the case for \$2.2 million. Thus, if S. 1053 is enacted, individuals and the EEOC will be empowered to bring suit against an employer on the same facts under both S. 1053 and the ADA.

Last year, the original sponsors of S. 1053 introduced similar legislation (S. 1995) that included an “election of remedies,” under which a plaintiff could sue under the genetics bill or the ADA, but not both. That provision is not in S. 1053. It should be re-inserted in the bill in order to prevent multiple lawsuits, double recovery and unnecessarily complex litigation.

## *Damages*

Given the lack of genetic discrimination and availability of significant protections under other laws, administrative enforcement and equitably based remedies (including loss of wages) should be sufficient to allay fear of possible discrimination while mitigating the risk of a dramatic increase in baseless and inherently expensive litigation. The inclusion punitive and compensatory damages will necessarily invite additional litigation, as was the case when such damages were made available under other discrimination laws. The courts already are inundated with employment litigation and certainly do not need the additional workload.

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